

My Pathway into the World of Disabilities Perspective from a Native American Parent

by Rhonda Talaswaima

It was not until after the birth of my son that I began my pathway into the world of disabilities. Prior to this, I never gave a second thought to those individuals who are disabled. This is probably typical of many people today. Many take it for granted that they can see the sun rise, hear your mother call your name, run or walk when you want, take part in a butterfly dance, hear the katsinas singing, read, write, understand simple directions, or even pick up a pencil. These are some of the challenges that our Hopi children and adults with disabilities experience every day.

It wasn't until my son's doctor started questioning me about his speech that I began to sense something. However, there were other signs before that could have alerted me. Looking back, this was part of my denial that many parents go through upon learning their child is different or disabled. When my son turned two and a half he started speech therapy at Tuba City, Arizona. Once a week for the next two years I would transport him 120 miles round trip; one hour going, one hour therapy, and one hour returning. This is what is called "lack of services". People with disabilities living on the reservations, or any rural community, deal with this on a daily basis.

The speech therapist had a box full of books on the floor. I remember picking out some books and taking them home to read. Some made me cry as I read about other mothers such as me. Yes, it is true, "first you cry". I remember going back to my nine months of pregnancy. What did I do wrong? What could have happened? I felt depressed and all alone. There was no one to turn to. I remember asking the speech therapist "Will he be able to talk?" The reply was, "Yes, but it may not be as complex as yours or mine". My son is speech and language impaired, learning disabled, and has symptoms of attention deficit

hyperactivity disorder.. I was depressed and in denial. My first contact with other parents was at the Hopi Junior-Senior High School. There was a person from Washington D.C. that wanted to meet with families of individuals with disabilities. This was where I met a parent of a child with Down Syndrome, a parent of a child with multiple disabilities, and a parent of a child with cognitive challenges. I cannot explain the "instant" connection. Later, I would meet other parents of children who were hearing impaired, visually impaired, and so on. Finally! Someone could understand how I was feeling! It is through these parents that I learned to accept or make adjustments in my life. I stopped questioning "why?" and started focusing on solutions.

It is these same parents that would later form what is now called the "Parent to Parent Support Group for Special Needs". It is through this group I learned to feel good about myself. I learned that I was not alone. Before this, there were many times that I felt like I was on an "emotional roller coaster". Many parents may experience depression, guilt, anger, and/or sometimes blame themselves for their child's disability. However, I prefer the word "adjust" rather than "accept". To me, accept implies that you are somehow better or above others by accepting them. Who am I to accept? Instead, I prefer the word "adjust". Yes, I have made adjustments to my son's disability. The first adjustment was to become educated about his disability. I became connected with Raising Special Kids (formerly known as Pilot Parents) in Phoenix, AZ. I began learning that knowledge is power. I also learned acronyms such as: IEP, SLD, LRE, IDEA, ADA, 504, and FERPA to name a few. I started attending every training that I could.

One unique training was sponsored by Pilot Parents of Southern Arizona. It is called "Partners in Policy Making" and is a

leadership program for parents of children with disabilities and self-advocates (individuals with disabilities who advocate for themselves). I have since been appointed to the Governor's Council on Developmental Disabilities. This is truly an honor. Parents of children or adults with disabilities need to continually educate themselves to effectively advocate for their family member who has a disability.

Many parents need emotional support to help them get through the early identification process. Then, parents need to understand that help early for their child is critical. My son was one of the children that "slipped through the cracks" when it comes to what is called "Early Intervention". He never had an Individualized Family Service Plan (IFSP). Many parents such as myself now recognize the importance of early identification and referral of children to appropriate resources. However, early intervention is only a small component of what it means to be disabled. Other issues include; education, inclusion, transition, assistive technology, housing, transportation, employment, and so forth. Then, there are the issues of dealing with those who would like to "turn back the clock" by changing some of the laws that parents and self-advocates have fought so hard for. This is called "backlash" and is happening now across the country in many courts where laws are being challenged.

Today I look at things differently. My son is such a special blessing for my family and me. Our family has grown in so many ways. He has made our family more sensitive and aware of many issues that face families with children or adults with special needs. He was the motivation for my returning to school a few years ago. He helps us to appreciate the things that many people take for granted. He attends school at the Hotevilla-Bacavi Community School on the Hopi reservation. Thank you to teachers like Ms. Gaudet, Ms. Keyesvah, Special Education Teacher, and Ms. Honani, Speech Therapist. His teachers have been extraordinary! Good teachers, an effective IEP, and supportive and involved parents can make a world of difference for a child with disabilities.

In closing, there is still so much work that needs to be done in our Hopi and other Native American communities for our children and adults that have disabilities (the term "disability" is a federal definition required for individuals to receive services). We need to start looking beyond the word "disability" and imagine the "possibilities". If you want more information regarding the Parent to Parent Support Group for Special Needs, contact Rhonda Talaswaima, Director of the "Office of Special Needs" P.O. Box 123, Kykotsmovi, Arizona 86039, or call 928-734-3411.